

Patient groups provide valuable support and advocacy for vulnerable people but funding the work can be difficult. **Alastair Kent** argues that not accepting industry money will limit the groups' effectiveness, but **Barbara Mintzes** believes that the money undermines their independence

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**NO** Patient groups provide information, advice, and support; represent patients on governmental committees; and speak in the media on behalf of patients. They can be a voice for someone who faces pain, invasive procedures, isolation, disability, and at times discrimination and poor medical care. However, a different view emerges in the pharmaceutical marketing literature, of "allies to help advance brand objectives".<sup>1</sup>

Can patient groups provide impartial information if they are funded by companies that sell products to treat those illnesses? I believe that the conflict of interest inherent in such a relationship makes this difficult. For patients there are three key risks:

- Disguised promotion channelled through a seemingly neutral third party
- Confusion between patients' and sponsors' interests in patient groups' policy
- Inadequate representation when those interests diverge.

#### How big is the problem?

Industry funding of patient groups is common. Ball et al examined websites of 69 patient groups for 10 chronic conditions; 37 (54%) disclosed funding sources, with 31 getting some industry funding.<sup>2</sup> In a random sample of US patient groups with annual revenues over \$100 000 (£50 000), 20 (80%) received industry funding and two (0.8%) did not accept it.<sup>3</sup> The four groups representing conditions associated with accusations of disease mongering had over 20% industry funding compared with 3/25 (12%) of the randomly selected sample.<sup>3</sup> A 2003 survey of Finnish patient groups found that 39 out of 55 (71%) received industry funding.<sup>4</sup> Rates of 33-60% have been reported in Ireland, Sweden, Germany, the UK, and Italy.<sup>5-9</sup>

#### Evidence of influence

With such widespread funding from drug companies we need to consider how this might affect the independence of patient groups. Industry sponsored research is more likely to report drug benefits than non-sponsored trials.<sup>10</sup> No similar systematic analyses

exist of patient groups, but support for sponsors' drugs and policies in funding companies' interest is common.

The Canadian Arthritis Society is well respected for its patient services. However, in 2000, the society's logo was used on newspaper supplements claiming safety advantages for celecoxib and rofecoxib without disclosing funding from the manufacturers.<sup>11</sup> In 2007, a fact sheet on the society's website called cox-2 inhibitors "an advance . . . in terms of safety and stomach protection," without mentioning cardiovascular risks.<sup>12</sup> The society has partnership guidelines and 6-7% industry funding.

In the United States, a 2001 memo from Merck disclosed in court shows that the company sought to use the Arthritis Foundation's pain management programme for promotion. The foundation's president was unaware of this but unconcerned: "We envision that as an educational program. Their marketing folks envision it as marketing."<sup>13</sup>

Cancer United, a patient group funded by Roche, which markets trastuzumab (Herceptin) and bevacizumab (Avastin) is run by the public relations company Weber Shandwick.<sup>14</sup> The group advocates full funding of cancer drugs in Europe. Another charity, Cancerbackup praised trastuzumab as "impressive" in early breast cancer without mentioning cardiotoxicity or funding from Roche; 9% of its funding is from industry.<sup>15</sup>

Emerging concerns about drug safety are highly relevant to patients but can also be overlooked. For example, the Asthma Society of Canada fails to mention concerns about higher asthma mortality with long acting  $\beta$  agonists in its treatment brochures.<sup>16 17</sup> The Irish depression group AWARE sees destigmatisation of antidepressant use as part of its mandate, but avoids participation in media debates on antidepressant risks.<sup>5</sup>

#### Pressure on reimbursement agencies

When the UK's National Institute for Health and Clinical Excellence (NICE) recommended restrictions on use of cholinesterase inhibitors, the Alzheimer's Society, which is partly funded by industry, mounted an intense lobbying campaign and joined donepezil's manufacturers in a legal challenge, despite unimpressive evidence of benefit. In British

Columbia, the only Canadian province not to fund these drugs, the Alzheimer's Society claims that some people get greater than average benefits but did not support a provincial initiative for double blind n of 1 crossover trials to determine coverage.<sup>18</sup>

Industry funded groups often exert strong pressure on governments to reimburse sponsors' drugs. Michael Rawlins, chair of NICE, warns, "In the long term it will do the patient organisations an immense amount of damage and the confidence in their neutrality will dissipate."<sup>19</sup>

Governments increasingly include public representatives on advisory committees and European legislation now requires this of the European Medicines Agency. Despite conflict of interest guidelines, these representatives are often selected from industry funded patient groups and networks. The European Patients'

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Forum represents patients at the medicines agency and the European Union Pharmaceutical Forum. The forum was

founded solely with industry funding and remains over 90% industry funded.<sup>20</sup> On its website, a report funded by Pfizer supports industry's "strong desire to provide more information than currently allowed" to consumers and patients.

The Association of British Pharmaceutical Industry's call for members to disclose charity funding is a positive step. Better national regulations governing charities are needed, to ensure full, easily accessible, and consistent disclosure. Are such steps sufficient? From the evidence, it seems that even small donations can affect a group's stance. A consumer group funded by telephone companies would not be trusted to judge the best mobile phone package, nor to be a public advocate on telecommunications policy. Is health less important?

**Competing interests:** BM is a research consultant with Health Action International, vice-president of DES (diethylstilboestrol) Canada, and on the Steering Groups of Women and Health Protection and Pharmawatch. These are consumer and patient groups without industry funding. She works with the Therapeutics Initiative, funded by the British Columbia Ministry of Health to carry out systematic drug reviews that are background reports for drug financing decisions, and as a clinical reviewer for Canada's Common Drug Review.

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